

1 **An exploration of pain experiences and their meaning in people with chronic obstructive**
2 **pulmonary disease (COPD)**

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ABSTRACT

Background: Pain is a common symptom in people with chronic obstructive pulmonary disease (COPD) which negatively influences quality of life and psychological well-being. However, our understanding of how those with COPD interpret the experience of pain is very limited.

Objectives: To explore how individuals with moderate to severe COPD experience pain.

Methods: Eight patients diagnosed with COPD who reported experiencing pain for greater than three months participated in in-depth interviews. Transcripts were subjected to interpretative phenomenological analysis.

Results: Five themes were identified: 1) Pain complicates the clinical profile of COPD; 2) Uncertainty of the pain experience: frustrations related to health care professionals' explanation for their pain and the need to legitimise; 3) Language and behaviour of pain: portraying pain as frustrating and unpredictable; 4) Psychological reactions towards pain: depression and fear-avoidance behaviour; 5) Altered identity perception: reduced self-worth, guilt in not meeting the expectations of others.

Conclusions: Patients report difficulty in explaining the persistence of pain. This fosters a need to legitimise their pain, which influences feelings of frustration and self-worth. An understanding of these responses will assist health care professionals in managing ongoing pain in those with COPD.

INTRODUCTION

1
2 Typical symptoms of chronic obstructive pulmonary disease (COPD) include dyspnoea, fatigue,
3 anxiety and depression, all of which reduce health-related quality of life (HRQOL) (Global
4 Initiative for Obstructive Lung Disease, 2015). The clinical profile of individuals with COPD is
5 further complicated by a growing number of studies describing self-reported pain symptoms,
6 with prevalence rates ranging from 37 to 96% (Bentsen, Rustoen, and Miaskowski, 2011; Borge,
7 Wahl, and Moun, 2011; HajGhanbari, Holsti, Road, and Reid, 2012; HajGhanbari et al, 2014; Lee,
8 Harrison, Goldstein, and Brooks, 2015; Lohne et al, 2010;).

9
10 The clinical implications of pain in COPD have predominantly been explored using
11 questionnaires, with a poorer HRQOL described in those with self-reported pain compared to
12 those who are pain free (Borge, Wahl, and Moun, 2011; HajGhanbari, Holsti, Road, and Reid,
13 2012; Synnott and Williams, 2004). While allowing for the collection of data on a large sample
14 size, the depth of information gleaned from these questionnaire-based studies is limited
15 (Beiske, 2001; McLeod, 2014). In the only qualitative study of individuals with COPD waiting
16 lung transplantation, Lohne et al (2010) described the co-occurrence of pain, breathlessness
17 and anxiety. However, there is a lack of information of the emotional and psychosocial impact
18 of pain in COPD and its influence on an individuals' ability to manage their disease. Fear-
19 avoidance of pain-provoking activities, such as exercise has been described in COPD
20 (HajGhanbari, Garland, Road, and Reid, 2013), but the full extent of fear-avoidance secondary
21 to self-reported pain is not well understood. In the absence of this knowledge, the

1 requirements for managing self-reported symptoms of pain in COPD and the expectations of
2 individuals for their pain management can only be speculated.

3
4 Given the limited understanding of self-reported symptoms of pain in COPD, the aim of this
5 phenomenological study was to understand the individuals' experience of pain through the
6 generation of rich and detailed descriptions. By obtaining this knowledge, a greater
7 understanding of treatment approaches required to achieve effective pain management and
8 minimise its clinical impact in those with COPD may be gained. This will inform current clinical
9 practice of health care professionals responsible for caring for patients with COPD who report
10 symptoms of pain.

11 12 **METHODS**

13 **Study design**

14 An Interpretative Phenomenological Analysis (IPA) was used to explore the meaning of pain
15 experiences (Smith and Osborn, 2009). Phenomenology aims to understand the meaning
16 attributed to a particular experience by exploring the participants' views and concerns (Smith
17 and Osborn, 2007; Smith and Osborn, 2009). It requires engagement and interpretation of that
18 participant's experience with a view to understanding how individuals with COPD make sense
19 of their pain (Smith, 2011).

20
21 Engaging patients in the planning and execution of research improves the applicability of study
22 findings and its translation into clinical practice (Domecq et al, 2014). In consultation with an

1 expert in IPA and based on previous experience (Harrison et al, 2015), we chose to include a
2 patient advisory group to review the questions prior to data collection. These members did not
3 participate in the in-depth interview process.

4

5 **Participants**

6 Sequential recruitment of participants enrolled in pulmonary rehabilitation at West Park
7 Healthcare Centre against the eligibility criteria was undertaken. Eligibility was based on a
8 clinical diagnosis of COPD with spirometry confirmation ($FEV_1/FVC < 70$) (Global Initiative for
9 Chronic Obstructive Lung Disease, 2015), a smoking history of greater than 10 pack years (one
10 pack of cigarettes per day for greater than 10 years) and reports of experiencing daily pain for
11 more than three months. Pain intensity was measured according to the Brief Pain Inventory
12 (BPI) (Keller et al, 2004), which has been previously used in COPD (HajGhanbari, Holsti, Road,
13 and Reid, 2012; Lohne et al, 2010). Individuals were excluded if they had a primary respiratory
14 diagnosis other than COPD, did not report pain or had an inability to communicate due to
15 language, hearing or cognitive impairment. All procedures were approved by the Human
16 Research Ethics Board. As the goal of IPA is to undertake a detailed interpretation of a specific
17 experience, a sample size up to eight participants was considered sufficient (Smith, 2011; Smith
18 and Osborn, 2009).

19

20 **Data collection**

1 Demographic data including gender, age and lung function were collated. Patients' pain
2 location(s), current pain treatment, and degree of pain interference were collected according to
3 the BPI (Keller et al, 2004).

4
5 An interview schedule comprising of open-ended and closed questions was developed, partially
6 informed by the findings of previous studies (Lohne et al, 2010; Scott-Dempster, Toye, Truman,
7 and Barker, 2014) and the views of the four patient advisory group members. In-depth
8 interviews were conducted by a physiotherapist (AL), who had 19 years of experience in
9 assessing and treating patients with COPD. AL introduced herself as a 'researcher' so
10 participants did not perceive her in a clinical role and therefore adapt their responses. The
11 interview schedule guided participants' responses, although interviews were participant-led
12 with individuals encouraged to tell their own stories (Table 1). The schedule ensured questions
13 stimulated narratives focusing on experiences of pain whilst allowing other topics, salient to the
14 individual, to emerge. A reflective diary was maintained during data collection by the
15 researcher (AL), who noted preliminary impressions to aid the overall analysis (Smith, 2011;
16 Smith and Osborn, 2007). All interviews were digitally recorded, with the duration ranging from
17 40 to 90 minutes. The aim of each interview was to explore participants' experiences of pain.

18

19 **Analysis**

20 All data from the interviews was transcribed verbatim with data stored and organised using a
21 computer software program (QSR NVivo version 9; QSR International, Doncaster, Australia).

22 Analysis was undertaken using IPA. AL conducted a line by line analysis of each original

1 transcript, recording exploratory comments describing the participant's experience and
2 understanding. The original transcripts were reviewed in detail by SH, a physiotherapist
3 experienced in the care of patients with COPD. Regular meetings between the two researchers
4 facilitated the development of emerging themes with significant exploratory comments. The
5 emerging themes were presented to three members of the patient advisory group who
6 provided feedback regarding the meaning of these experiences (Smith and Osborn, 2007; Smith
7 and Osborn, 2009). Following confirmation of the emerging themes, they were applied across
8 the data set, and were labeled as master themes (Smith, 2011; Smith and Osborn, 2009). The
9 master themes were presented to five multidisciplinary health care professionals experienced
10 in the care of patients with COPD, who were asked to contextualise the findings while
11 considering them from the viewpoint of the patients. The inclusion of a patient advisory group
12 and health care professionals during the analysis phase has been previously applied (Clarke et
13 al, 2014; Harrison et al, 2015) and was used in this study to ensure the breadth of
14 interpretation and to incorporate a form of triangulation (Malterud, 2001). Additional expertise
15 was sought from a third researcher (DB) who assisted in agreeing the final master themes.
16 Relationships between themes were identified.

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RESULTS

19 The eight participants experienced pain in a variety of locations (most frequently upper and
20 lower back and lower limb) with an average intensity of 5/10 (Table 2). Five master themes
21 were identified.

22

1 **1. Pain complicates the clinical profile of COPD**

2 A connection between pain and dyspnoea was expressed in patients' narratives: *"And it makes*
3 *it really hard to breath. Every breath you take I get the stabbing pain with it."* (PID2). *"You're*
4 *trying to get your breath; you can't get your breath. The harder you breathe the worse the pain*
5 *and just that's a vicious cycle. One goes with the other"* (PID5). Individuals perceived
6 breathlessness as a cause for their pain, but pain also exacerbates breathlessness: *"As far as*
7 *breathing, when I start breathing hard it starts, the pain comes on really quick"* (PID5).

8 However, pain and shortness of breath were distinguished as independent symptoms by two
9 patients: *"My breathing is still the same as what it was and the pain has got nothing to do with*
10 *it"* (PID4). *"They're separate things. Usually it's either the pain or the short of breath"* (PID8).

11

12 Pain appeared to contribute to fatigue and difficulty clearing secretions: *"And then that starts*
13 *scaring me because when I don't have enough breath then I start getting more and more mucus*
14 *on my chest"* (PID2). *"It does affect how tired I get just being in pain takes a lot out of you"*
15 (PID1).

16

17 Pain served as a negative distraction and individuals described a sense of being overcome by
18 pain, which limits concentration. This encourages heightened sensitivity and awareness of pain:
19 *"I can't even think about what is happening other than trying to get rid of the pain"* (PID7).
20 *"When it's really bad, I can't think straight. Everything is fuzzy and it seems like I'm in a bubble"*
21 (PID2).

22

1 **2. Uncertainty of the cause of pain**

2 A sense of distrust, dissatisfaction and frustration with HCPs was portrayed, arising from
3 uncertainty about the cause of pain in six participants, despite medical tests and investigations
4 and a lack of effective management strategies: *"I don't know what caused it. I really don't but it*
5 *sure is annoying"* (PID3). *"They haven't been able to find anything so that's it"* (PID3). *"They've*
6 *lumped it under the category of...because they've been unable to determine what's causing it"*
7 (PID1). Two participants attributed pain to be secondary to osteoarthritis or soft tissue damage:
8 *"They're thinking right now it's tightened muscles and tendons"* (PID7). Feelings of being
9 dismissed were expressed and rendered individuals doubtful of their own pain experience: *"I*
10 *don't know if that's psychological pain or what? Am I thinking I'm feeling pain? And then I just*
11 *think of why they're going to tell me it's in my head anyways?"* (PID2). *"I feel the pain but*
12 *without a cause you start to doubt yourself, perhaps it's in your head but you are feeling pain.*
13 *They can't seem to tell me what it is"* (PID5). Ambiguity surrounding the cause of pain fostered
14 a need to bolster the legitimacy of pain experiences: *"It hurts believe me. Hurts so frigging bad.*
15 *And I can take quite a bit of pain you know"* (PID5). *"It's really tough on me. Believe me. It's*
16 *hard to describe it"* (PID7).

17

18 **3. Language and behaviour of pain**

19 Intense imagery was used to convey pain as sharp or dull, aching or burning: *"It's a terrible*
20 *throbbing and aching sensation"* (PID3). *"Like fire, really hot and like somebody's stabbed me*
21 *with a knife. Sometimes man it's like somebody took a knife just takes it and grinds it around"*
22 (PID5). *"Very sharp, sharp like a knife would be and radiates pain in the area, but it's extremely*

1 *sharp*" (PID1). Patient narratives reflect the emotional impact of pain, articulating fear and
2 feelings of being overwhelmed by pain: *"That's a real terrible aching feeling. That one is the*
3 *scary one, like it scares me a lot too right.."* (PID6). The language used to describe pain reflected
4 its negative influence on their mood: *"It feels cranky, stabbing, bitchy"* (PID2).

5
6 Pain was conveyed as unpredictable and fluctuating in intensity, which influences an
7 individual's response to their pain: *"But it's there just constantly and it never ever goes away"*
8 (PID1). *"I don't know how to get away from it. It just seems to chase me"* (PID2). Individuals
9 portrayed a sense of resignation, believing that pain should be tolerated: *"Right now it's hurting*
10 *me. It lasts for hours, maybe all day each day. It's just not to the point where I am going to cry*
11 *tears"* (PID8). *"You know when it comes on, and it stays and I just hope that it gets over quickly*
12 *but sometimes it does, sometimes it don't"* (PID3). A sense of control is expressed when faced
13 with temporary pain and enduring pain is met with resilience and stoicism: *"I can cope with it*
14 *when it's going to be a temporary pain and you know it's going to happen you know"* (PID7).
15 *"I've gotten used to living with the pain. I know that I can't do anything about it, but I don't let it*
16 *control me"* (PID1).

17

18 **4. Psychological reactions towards pain**

19 Feelings of being all consumed by pain were coupled with a heightened sense of low mood: *"I*
20 *guess it did get you a little bit depressed knowing that you can't sort of get out of that hole*
21 *right?"* (PID3). *"Like it's getting harder. Just sometimes it's just unbearable"* (PID6).

1 Feelings of despair, entwined with misery and anger towards self, fostered irritability: *"I feel like*
2 *crap. Well it hurts, who wants to hurt? I mean, I don't want to hurt. It's not fun"* (PID5). *"I get*
3 *pissed at myself for being in that pain and then I try to figure out why. Why do I put up with it?*
4 *Why does it happen to me?"* (PID2). *"I have given up, I can't do nothing"* (PID2). Rumination
5 surrounding pain was prominent throughout the transcripts and when coupled with concern for
6 the future, appeared to render an individual overwhelmed: *"I'm not a suicidal watch but it's*
7 *gotten to a point in the past I was like I've got it all figured out how I'd do it"* (PID2).
8 A sense of being defeated by pain resonated with individuals who described trying multiple
9 treatment strategies that were ineffective: *"I've tried heat in the past, didn't work, tried ice in*
10 *the past, didn't work"* (PID2). *"It works sometimes. It's hit or miss most days. You never know"*
11 (PID3).

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14 The anticipation of pain provokes fear, promoting avoidance of activities thought to aggravate
15 pain: *"And the walking exercise I try to do it because I know it's good for me other than just the*
16 *knee but it hurts."* (PID8). *"Like I get frozen there sometimes right because I know it's painful*
17 *and I'm afraid..."* (PID6). This resulted in a sense of loneliness and isolation that was prominent
18 in individuals' narratives: *"I don't even go out, I stay home. For me to go out, I have to walk*
19 *down the stairs and that's so hard I can't even do that. So I say no"* (PID6).

20

21 **5. Altered identity perception**

22 An inability to fulfill self-expectations was expressed, lowering self-esteem and diminishing self-
23 worth: *"I don't feel productive"* (PID6). *"Like when you've done something your whole frigging*

1 *life and all of a sudden one year you've got to like ten percent from what you could do last year"*
2 (PID7). A sense of grief and frustration for the loss of the person they once were and the
3 activities they used to enjoy was prominent throughout the transcripts: *"I'm just a piece of skin*
4 *on bones that doesn't do a hell of a lot anymore because of my pain"* (PID7).
5
6 Feelings of frustration with pain and its impact on others were expressed. This in turn, resulted
7 in a greater sense of guilt and self-blame: *"Makes me feel bad because being in pain, I'm*
8 *making their life miserable because I'm cranky with them, short-tempered"* (PID2). *"Pain makes*
9 *you depressed, then you start getting anxious ...And once I get grumpy then I start getting*
10 *irritating to everybody around me. Then life just falls apart"* (PID7). A sense of failure was
11 prominent throughout the transcripts both in terms of meeting work expectations and in
12 fulfilling family roles and responsibilities: *"It's just somebody else doing the work and I'm not*
13 *helping. I wasn't raised that way"* (PID6). *"The disease as a whole yes obviously it does, it makes*
14 *me less the patriarch....it's a much stronger reliance on my wife than there should be"* (PID1).
15 Guilt was accompanied by fear of being unable to sustain employment, resulting in a loss of
16 ambition: *"It really, really stops your flow of motion and when I have no flow of motion then I*
17 *have no ambition. It takes away from what you can do, then it takes away from what you want*
18 *to do"* (PID1). *"You get that type of stress, do I have a job tomorrow or not and that plays on the*
19 *mind which plays on the body, which plays on the heart, which plays on the lungs.."* (PID5).
20

21 **DISCUSSION**

1 This phenomenological study describes the experiences of self-reported pain in individuals with
2 COPD. The unrelenting nature of pain, coupled with the uncertainty regarding its cause, is a
3 source of frustration, prompting rumination, anxiety and low mood. The interaction between
4 pain and other symptoms such as dyspnoea encourages fear-avoidance behaviour and social
5 isolation.

6
7 Despite the absence of a formal diagnosis of chronic pain, parallels can be drawn between the
8 findings of the current study and those of chronic pain populations. The desire for an
9 explanation of the cause of pain is common among those with chronic pain in the absence of
10 COPD (Corbett, Foster, and Ong, 2007; Toye and Barker, 2012). Patients' inability to make
11 sense of their pain leads to worry, confusion, distress and vulnerability (Davis, Zautra, and
12 Reich, 2001; Keefe et al, 2001; Lansbury, 2002; Lumley et al, 2011; Purdie and Morley, 2015). In
13 this study, the absence of a definitive cause may foster patients' perception that their pain is
14 being dismissed or met with skepticism by HCPs. For some individuals, this has led them to
15 question the credibility of their pain. This sense of dismissal may have contributed to patients'
16 use of vivid descriptions to bolster legitimacy of pain, especially in the absence of a diagnosis
17 (Lillrank, 2003) or effective treatment strategy.

18
19 In the current study, persisting pain was noted to interfere with concentration as well as
20 increase anxiety and rumination, findings which are consistent with chronic pain populations
21 (Cai and Oderda, 2012; Davis, Zautra, and Reich, 2001; Keefe, et al, 2001; Lansbury, 2002;
22 Lumley et al, 2011; Purdie and Morley, 2015). Low mood also appeared to be present in some

1 patients in the current study. Depression is a common comorbidity in COPD (Yohannes and
2 Alexopoulos, 2014) and mood changes secondary to pain can impose an additional
3 psychological burden. Low mood can exhibit a deleterious effect on function and social
4 interaction in people with COPD (Dalal, Shah, Lunacsek, and Hanania, 2011; Doyle et al, 2013).
5 For those diagnosed with chronic pain without COPD, treatment for pain does reduce
6 depression (Holmes et al, 2012). For this reason, understanding the added contribution of pain
7 to low mood is important in the management of COPD.

8
9 The experience of pain as unpredictable and unrelenting has been linked to fear avoidance
10 behaviour in people without COPD experiencing chronic pain (Vlaeyen and Linton, 2000). Our
11 findings of avoiding activity due to pain are consistent with pain related fear of injury reported
12 in a questionnaire-based study of individuals with COPD and pain (HajGhanbari, Holsti, Road,
13 and Reid, 2012). Pulmonary rehabilitation is a highly effective treatment for those with COPD
14 (McCarthy et al, 2015) and back and lower limb pain have already been identified as reasons for
15 failing to complete a program of pulmonary rehabilitation (Keating, Lee, and Holland, 2011).
16 Together with the findings in the current study, this highlights the importance of health care
17 professionals being aware of avoidance of activity due to fear of pain in those with COPD.
18 Treatment strategies that specifically address this concern may be necessary when treating pain
19 in people with COPD.

20
21 The combined presence of pain and dyspnoea and their cycle of interaction has previously
22 identified in those with end-stage COPD (Lohne et al, 2010). This vicious circle of pain and

1 dyspnoea with one symptom triggering the other suggests a link between symptoms. However,
2 this relationship is complex, the true extent of this connection is not completely understood
3 and warrants further exploration.

4
5 Falling short of others' expectations was voiced by individuals in this study and is consistent
6 with older people with chronic pain (Hulsebusch, Hasenbring, and Ruse, 2015; Lansbury, 2002).

7 The challenge to maintain a valued sense of self in the current study is also consistent with
8 descriptions of difficulties sustaining self-regard or dignity for people with chronic pain (Smith
9 and Osborn, 2007). Those with COPD already struggle with self-worth (de Oliveira et al, 2015);
10 pain may further negate this perception. Chronic pain exacerbates loneliness (Purdie and
11 Morley, 2015; Smith, 2011;) and is associated with retreating from social situations to avoid
12 negative social interactions (Hellstrom, 2001). Social isolation and confinement is already
13 experienced by people with COPD due to dyspnoea and the effects of inactivity (Gardiner et al,
14 2010). This inability to socialise has contributed to a state of loneliness in this population (Ek
15 and Ternstedt, 2008). Experiencing pain in addition to dyspnoea and inactivity may amplify
16 the extent of social isolation and a reduced sense of self-worth in those with COPD. For this
17 reason, treatment approaches for people with COPD suffering pain may need to include
18 interventions that address these psychological consequences within a management plan.

19
20 The strengths of this study originate from the in-depth interviews, designed to illustrate the
21 complex experience of individuals with COPD living with pain. A phenomenological enquiry
22 typically involves a small number of patients. The aim of an interpretive phenomenological

1 study is to glean a rich and detailed understanding about the experience of interest, in this
2 instance the experience of pain in individuals with COPD, rather than drawing generalisations
3 (Smith, 2001). This type of approach generates future hypotheses to be explored. The
4 incorporation of a patient advisory group as well as a collaborative workshop of health care
5 professionals supports the plausibility of the interpretations.

6

7 This study has shaped the direction of an ongoing body of work, which will examine the role of
8 pain in the pulmonary rehabilitation experience and the effects of pulmonary rehabilitation on
9 pain in patients with COPD. This will inform the development and content of a pain
10 management program specifically designed for patients with COPD suffering from pain.

11

12 Individuals with COPD experiencing pain express frustration when its origins are not
13 understood, with a need to legitimise their experience. They convey feelings of reduced self-
14 worth and social isolation and describe a link between symptoms of breathlessness and
15 symptoms of pain. Pain appears to contribute to fear-avoidance behavior and a tendency to
16 withdraw from social contact. These experiences of living with pain need to be considered
17 when determining the most appropriate physical and psychosocial management of pain in
18 people with COPD.

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DECLARATION OF INTEREST

The authors have report no declarations of interest.

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